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13. ABSTRACT (Maximum 200) Survey 1 has been given to 77 women. Recruitment has been lower than anticipated in this first year for several reasons. First, not until May 1997 were we able to hire an African American genetic counselor. Second, it is recommended that the women undergo ovarian screening. As the Breast Examination Center of Harlem (BECH) does not offer free ovarian screening and a number of our participants do not have health insurance, recruitment was slowed down while we identified hospitals and clinics that provide screening at low or no cost. Third, the number of high risk women attending the BECH clinic has been lower than we expected. We have initiated contacts with other recruitment sites and by recruiting more broadly expect to be able to recruit more high risk women. Fourth, a number of the women recruited from the BECH clinic did not return their questionnaires, we now offer the women the opportunity to make an appointment to complete the questionnaire with the research assistant. As we have been able to address these start up obstacles, we anticipate that recruitment will improve during the remaining years of the study. With the support from this award we have 1 paper in press, and 1 published abstract.				
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## Introduction

Recent molecular studies have identified a major breast cancer-ovarian susceptibility gene, termed BRCA1, on chromosome 17 and BRCA2 on chromosome 13 (Ford et al., 1995;1995). Depending on the population studied, women with mutation in BRCA1/2 have 40% to 85% cumulative risk of developing breast cancer and 5% to 60% cumulative risk of developing ovarian cancer (Strewing et al., 1997; Whittemore et al., 1997; Schrag et al., 1997). Genetic testing for breast cancer has important health implications as it offers new opportunities for cancer prevention and early detection. However, genetic testing can also have adverse psychological consequences, including loss of insurance, stigmatization, and increased psychological distress (Croyle et al., 1997; Bankowski et al., 1991; Beckwith, 1991; Holtzman, 1989). Most of the studies of the impact of counseling and genetic testing have predominantly focused on Caucasian women and have paid little attention to the role of ethnicity. Several lines of research suggest that minority women may have different attitudes toward genetic testing and that they may react differently to notification of test results. For example, compared to white women, women of African descent have been found to have less cancer knowledge (Michielutte et al., 1982); to be less likely to utilize screening methods for breast cancer (Vernon et al., 1991); and to have higher levels of cancer anxiety (Miller et al., 1994). Further, research on sickle cell carrier screening programs indicated that insufficient information and counseling resulted in confusion, stigmatization, and discrimination among African-American gene carriers (Wilford and Fost, 1990; Hill, 1994). This experience may have resulted in skepticism and distrust of the medical research community. In order for genetic testing to be successfully implemented in minority populations, it is essential to: 1) identify factors that predict interest in testing; 2) examine the impact of genetic counseling on interest in genetic testing; and 3) determine the impact of risk notification on psychological adjustment and screening behaviors.

The present research examines these issues among urban women of African descent. We decided to focus solely on this group of women to allow us to examine various subgroups within this ethnic group. The major aims of the study are to: 1) identify factors that are associated with interest in genetic testing; 2) demonstrate the psychological effects of genetic counseling for women with family history of breast cancer; and 3) measure the impact of risk notification based on genetic testing and its effects on psychological functioning and preventive and early detection behaviors. To achieve these aims three interrelated studies are being conducted. Study 1 is a cross-sectional study examining factors influencing interest in and readiness to undergo genetic testing at the time of entry into the surveillance program. Study 2 is a longitudinal investigation of whether genetic counseling increases knowledge and promotes readiness to undergo genetic testing. Study 3 consists of pre- and post-notification evaluation of the psychosocial impact of DNA testing.

## Body

Study 1 is a cross-sectional study of African American women at varying risk for breast cancer. The overall aim of this study is to identify cognitive, emotional, and other factors that influence

interest and readiness to donate a blood sample for BRCA1 testing.

**Procedure:** African American women scheduled for an appointment at the Breast Examination Center of Harlem (BECH) are being recruited. At the time of their visit the research assistants explain the study to eligible women (see Eligibility Criteria in the grant application) and interested women receive Survey 1 (see Psychobehaviour Measures, Section 4, in the grant application).

### **Results:**

**Results:** To date, Survey 1 has been given to 77 women. As indicated in the Statement of Work (see grant application) we had anticipated that we would be able to recruit 170 women during Year 1. Recruitment has been lower than anticipated in this first year for several reasons. First, we thought that it was important that the genetic counselor recruited for the study be sensitive to African American community issues. The recruitment process to that end took longer than we had anticipated. Not until May 1997 were we able to hire Ms. Duteau who is an African American genetic counselor. Ms. Duteau had previous experience in pre-natal counseling but no prior training in cancer counseling. Consequently, she received extensive training in cancer counseling over a 2 month period at the clinical genetics service at Memorial Sloan-Kettering Cancer Center (MSKCC). Ms. Duteau now has an office at Memorial's breast examination center of Harlem and devotes her time to counseling the subjects recruited for this study. Second, appropriate clinical practice dictates that in the counseling session some women, particularly to those who have BRCA1 mutation, be recommended to undergo ovarian screening. As the BECH does not offer free ovarian screening and a number of our participants do not have health insurance, it became important to identify hospitals and clinics that provide screening at low or no cost. Recruitment was slowed down while we identified these hospitals and clinics. Third, the number of high risk women attending the BECH clinic has been lower than we expected. To address this problem, we have initiated contacts with other recruitment sites and by recruiting more broadly expect to be able to recruit more high risk women in Year 2 and 3 of the study. Fourth, we found that the women recruited from the BECH clinic were much less likely to return mailed questionnaires than has been our experience at other MSKCC clinics. To address this problem we now offer the women the opportunity to make an appointment to complete the questionnaire in the clinic and/or over the phone with the research assistant. As we have been able to address these start up obstacles, we anticipate that recruitment will improve during the remaining years of the study.

**Study 2** is a longitudinal evaluation of genetic counseling for African American women at varying risk for breast cancer. The overall aim of this study is to examine the impact of genetic counseling on distress, breast cancer knowledge, and readiness to donate a blood sample for genetic testing.

**Procedure:** Participants who complete Study 1 are eligible for study 2. Women who are at high risk (relative risk  $\geq 20$ ) for breast cancer are invited to receive individual genetic counseling and women who are at low risk for developing breast cancer (relative risk  $< 20$ ) are invited to

participate in a professionally-led group discussion. Women who express an interest in genetic testing after their counseling sessions are offered to donate a blood sample for BRCA1 testing. Approximately 2 weeks after their genetic counseling Survey 2 is mailed to participants, after completing the Survey the participants mail it back in a pre-paid mailer. Participants who decide not to receive the genetic counseling are mailed a copy of Survey 2 to complete at timepoints comparable to individual who undergo the counseling.

**Results:** To-date, 10 low risk women and 11 high risk women have undergone counseling. As indicated in Statement of Work we had anticipated that 28 high risk women and 45 low risk women would be counseled during Year 1. However, as we encountered several unanticipated problems in starting the study (see explanation for Study 1) we were unable to attain our goal. However, as we have been able to address the beginning obstacles we anticipate that recruitment will greatly improve in Year 2.

**Study 3** is a longitudinal evaluation of the psychological and behavioral impact of genetic testing for BRCA mutation. The overall aim of this study is to examine the impact of receiving positive vs. negative test results on psychological functioning as well as prevention and early detection behaviors.

**Procedure:** Subjects who elect to receive their test results are informed in accordance with IRB protocol #93-102 or #96-51 (i.e., appropriate post-test counseling will be provided). To assess acute distress and to monitor participants' well-being following notification, brief psychological measures are administered immediately after subjects notification session and again 10 days later. Follow up surveys (see Measures, section 4 in the grant proposal) are mailed to all subjects approximately 1 (Survey 3a), 6 (Survey 3b) and 12 (Survey 3c) months after their notification session.

**Results:** To-date 8 subjects have received their results, 4 subjects declined to learn the test results, and 4 are awaiting their results. As indicated above we are behind in subject recruitment but anticipate that recruitment will be greatly improved during Year 2.

### **Conclusions**

Recruitment to date includes: 1) 77 women who have been recruited for Survey 1; 2) 22 women who have undergone counseling and completed Survey 2; and 3) 16 women who have donated blood for genetic testing. As indicated in Statement of Work (see grant application) we anticipated that the present research would be further along than it is. As indicated above we had several start up obstacles which we have been able to address and therefore anticipate that recruitment will be greatly improved during the remaining years of this research.

With the support from this award we have 1 paper in press and 1 published abstract



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## **Appendix**

1. Abstract
2. Paper in Press

## SYM 2B

### GENETIC COUNSELING AND TESTING FOR BREAST CANCER SUSCEPTIBILITY AMONG WOMEN WITH FAMILY HISTORIES OF BREAST CANCER

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Genetic counseling is important for women who are considering genetic testing for breast cancer susceptibility. However, to date, relatively little is known about the impact of individualized genetic counseling on: perceived risk for breast cancer susceptibility, emotional distress (general and cancer specific) and decision making about genetic testing. In an ongoing study we are examining these issues among women with at least two first degree relatives with breast cancer. Two weeks prior to the counseling session and 2 weeks after the counseling session the women completed measures of: general distress (Brief Symptom Inventory); cancer specific distress (Impact of Event Scale); readiness to undergo genetic testing; and perceived risk for breast cancer susceptibility. In addition, after the counseling, the women are offered the opportunity to undergo free genetic testing. Preliminary results indicate that the genetic counseling is effective in reducing perceived risk for breast cancer to levels consistent with empiric genetic risk, and in reducing cancer-specific distress. No change was seen in general distress. Prior to the counseling 60% of the women indicated that they were ready to undergo genetic testing and 40% indicated that they were not yet ready. After the counseling 66% of the women who had indicated that they were ready underwent genetic testing and 35% of the women who had indicated that they were not yet ready underwent genetic testing. These results suggest that individualized genetic counseling may play an important role in women's decision making regarding genetic testing. The impact of positive and negative test results on perceived risk and distress will also be discussed.

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**Title: Cancer-Specific Distress is Related to Women's Decisions to Undergo BRCA1 Testing**

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**Cancer Research Therapy and Control: In Press**

### Abstract

**Problem:** To examine the role of demographic variables, objective risk, perceived risk and cancer-specific distress in women's decisions to undergo genetic testing

**Methods:** One-hundred and five women with family histories of breast cancer completed a baseline questionnaire after which they were invited to attend a genetic counseling session and provide a blood sample for BRCA1 testing

**Results:** Fifty-five percent of the participants provided blood samples. After controlling for age, objective risk and perceived risk, which were positively related to provision of blood sample, women with moderate levels of cancer-specific distress were more likely to provide a blood sample than women with high or low levels of cancer-specific distress.

**Conclusions:** Cancer-specific distress affects women's decisions to undergo genetic testing for BRCA1. Genetic counseling needs to address cancer-specific distress, since it may increase the probability that individuals are making an informed decision about undergoing genetic testing for breast-cancer susceptibility.

## Introduction

Consistent with risk estimates for most common cancers, women with histories of breast cancer in even one first-degree relative have been found in large epidemiological studies to be more than twice as likely to develop breast cancer themselves (1). A history of additional affected close relatives further increases the risk, as do other characteristics (e.g., bilateral disease, diagnosis at an early age) associated with a role for heredity in the etiology (2,3). Segregation analyses of families with multiple cases of breast and/or ovarian cancer suggest the existence of rare, autosomal dominant susceptibility genes (2,4). Linkage analyses has led to the identification and subsequent cloning of two large genes, BRCA1 on chromosome 17 and BRCA2 on chromosome 13; mutations in these genes are now thought to be responsible for the majority of breast cancer cases in families with four or more affected relatives (2). Depending on the population studied, women with mutation in BRCA1/2 have 40% to 85% cumulative risk of developing breast cancer and 5% to 60% cumulative risk of developing ovarian cancer (5-7).

For women with family histories, there are several benefits associated with genetic testing for breast cancer susceptibility (8). For example, women found to be mutation carriers can increase the probability that breast cancer will be detected at early stage by increasing their breast cancer surveillance behavior (e.g., mammography), or they can decrease the probability that breast cancer will develop by undergoing prophylactic mastectomy (9,10). In addition women who learn that they do not carry a cancer-predisposition mutation may experience relief and improvements in quality of life (8). However, there are also several negative consequences associated with genetic testing (8). For example, women found to be mutation carriers may face uncertainty about their future, insurance discrimination, and worsened quality of life (11).

Consequently, individuals considering genetic testing need to weigh the benefits against an array of possible costs of genetic testing. There are probably several factors that affect individuals' decision to undergo genetic testing. Intentions to undergo genetic testing for cancer susceptibility have been found to be related to younger age (12), higher education (12) and higher levels of perceived risk (13) and higher levels of cancer-specific distress, as assessed by the intrusion subscale of the Impact of Events Scale, IES (12,14). However, as intention to undergo genetic testing may not result in actual test (15) use, relatively little is known about predictors of actual test use. In two recent studies (16,17), variables found to be positively related to requests for BRCA1 test results included: being a female, younger age, more education, higher levels of objective risk, having health insurance, and higher levels of cancer-specific distress (IES). The participants in these studies were members of hereditary breast ovarian cancer (HBOC) families. They had provided blood samples several years earlier as part of studies conducted to localize the BRCA1 gene, and knew that a BRCA1 mutation had been identified in their family. Therefore, it is not clear if similar results would be obtained with individuals with less extensive family histories of breast cancer and no history of participation in genetic studies.

The possibility that cancer-specific distress may have a different impact on the decision to undergo genetic testing among women with less extensive family histories of cancer is raised by studies that have examined breast cancer screening behavior. These studies have found that high levels of psychological distress, assessed by a variety of measures, were related to reduced compliance with appropriate screening practices, including mammography, clinical breast-examination, and breast self-examination (18-20). On the other hand, there have also been reports that high levels of distress about breast cancer facilitate appropriate screening practices

(21,22). It has been suggested (23) that one of the reasons for these apparently contradictory findings is that the relation between distress and screening practices is curvilinear; too much or too little distress may inhibit screening while moderate levels of distress may facilitate screening.

The purpose of the present study was to examine the relation between demographic variables, objective risk, perceived risk, cancer specific-distress and decision making about BRCA1 testing among women with family histories of breast cancer who had not previously received genetic counseling or participated in genetic studies. Based on the above reviewed literature we expected that education, objective risk, and perceived risk would be positively related to provision of a blood sample for BRCA1 testing. We also expected that women with moderate levels of cancer-specific distress would be more likely to provide a blood sample for BRCA1 testing than women with low or high levels of cancer-specific distress.

## Methods

### Subjects

Participants were 105 women who were participating in an ongoing longitudinal study examining the psychological and behavioral impact of genetic counseling and testing for breast cancer susceptibility. The women were recruited from two clinics at Memorial Sloan-Kettering Cancer Center, the Special Surveillance Breast Program (SSBP N=62) and the Clinical Genetics Service (CGS, N= 43). To be eligible for the study the women had to: 1) be 18 years of age or older; 2) have at least one first-degree relative diagnosed with breast cancer; 3) have no personal history of cancer; 4) have never undergone genetic counseling for breast cancer; 5) be able to read and write English; and 6) willing to provide informed consent.

### Procedure



Women who were scheduled for a routine mammography at a special surveillance breast clinic or self-referred for genetic counseling were contacted by telephone approximately one to two weeks prior to their scheduled appointment. The study was described as an investigation to learn more about women's attitudes and feelings about breast cancer and genetic testing for breast cancer susceptibility. Participants were told that they would be asked to complete questionnaires several times over the course of the study and that they would have the opportunity to undergo genetic testing, free of charge to determine whether or not they carry a mutation in the BRCA1 gene. It was emphasized to the women that they could: 1) refuse to participate; 2) discontinue their participation at any time; 3) fill out the questionnaires without going for genetic counseling or genetic testing; 4) attend the counseling session without undergoing genetic testing; and 5) decide not to learn their mutation status once their test results were available. It was also emphasized that the women could not undergo genetic testing unless they had attended the counseling session.

Women who met the study criteria and were interested in participating were mailed a consent form, the baseline questionnaire package, and a pre-stamped envelope. A few days later the women were contacted again by telephone to verify that they had received the questionnaire package, review the consent form, and answer any questions that they might have. The women then returned the signed consent form and the completed questionnaires prior to their genetic counseling visit (see below).

Women at relatively high risk (relative risk  $\geq 2$ ) for breast cancer who had signed the consent form and returned the completed questionnaires were invited to come in for individual genetic counseling. The counseling sessions were conducted by a genetic counselor and lasted

one to two hours. After construction of the pedigree, the following issues were addressed: 1) possible reasons for familial clusterings of cancer; 2) the likelihood of the occurrence of cancer in the pedigree to be hereditary (i.e. conforming to the criteria for a hereditary cancer syndrome) or familial (i.e. not meeting those criteria); 3) limitations of pedigree analysis, including the inability to distinguish between a sporadic and inherited cancer; 4) the relative importance of various risk factors other than family history; 5) risk estimates for developing cancer based on family history and/or associated with BRCA mutations; 6) options for prevention and early detection, and their limitations 5) limitations and benefits of genetic testing for BRCA1; and 6) risks of receiving test results, including insurance discrimination and adverse psychological consequences.

After the genetic counseling, subjects were given the opportunity to provide a blood sample to be tested for mutation in BRCA1. For subjects who decided to undergo genetic testing, a separate informed consent for DNA testing was reviewed and participants were urged to consider the impact of negative, positive, and ambiguous results. It was also stressed that participants could decide not to learn their results once they became available.

Women at relatively low risk for breast cancer (relative risk  $< 2.0$ ) followed the same procedure as the women at relatively high risk, except they were invited to attend a group genetic counseling session which addressed the same issues as the individual counseling.

### Measures

Demographic questionnaires: Age, education, race/ethnicity and marital status were assessed using a standard self-report form (24).

Family history questionnaire: This questionnaire is designed to assess the occurrence of

cancer in participants' biological first- and second-degree relatives. Participants are asked to supply detailed information about their family histories of cancer, e.g., ages of onset and occurrence of multiple cancers. The data from this questionnaire was used by one of us (KB), a genetic counselor kept blind to all other study data, to estimate lifetime objective breast cancer risk.

Perceived risk of breast cancer: Following previously published methods (24-26), subjects rated on a scale from 0% (not at all likely) to 100% (extremely likely) their perceived likelihood of developing breast cancer in their lifetime.

Impact of Event Scale: (IES; (27)). The intrusion subscale of the IES was used to assess breast cancer-specific distress. This seven-item subscale assesses frequency of intrusive thoughts about a specific stressor, in this case, the threat of breast cancer. The coefficient alpha in the present sample was .88, consistent with values reported by Horowitz et al., (27). Subjects indicated how frequently each thought or behavior occurred "during the past week including today". This measure was selected as Lerman, Schwartz et al (17) found that intrusive thoughts about breast cancer were related to BRCA1 test use.

## Results

### Characteristics of the study population.

The mean age of the sample was 45.1 years (SD=9.3; range 21 - 72), The majority of the women were white (91%), well educated (75% had attended college) and married (61%). The mean perceived risk was 59.2% (SD=26.5; range 0-100) and the mean objective risk was 28.5% (SD=13.3; range 11%-50%). For the cancer-specific distress measure, the mean score on the IES intrusion subscale was 6.3 (SD=7.5; range 0-31). Fifty-five percent of the participants

(N=58) provided a blood sample for genetic testing.

Are sociodemographic variables, objective risk and perceived risk related to who provides a blood sample for genetic testing?

To determine the bivariate correlates of blood provision we conducted a series of  $\chi^2$  analyses. Specifically, we evaluated the associations of sociodemographics, objective risk, and perceived risk with blood provision. Because the distribution for both perceived risk and objective risk was skewed these variables were dichotomized based on a median split. Following the procedure by Lerman and colleagues, (17) age was dichotomized as  $<50$  vs.  $\geq 50$  years.

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Insert Table 1 about here  
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As shown in Table 1, older women tended to be more likely to provide a blood sample for genetic testing,  $\chi^2 (1, N=105)=3.4, p = .06$ , and women with higher levels of perceived and objective risk were significantly more likely to provide a blood sample for genetic testing ( $\chi^2 (1, N=105)=4.2, p = .04$ ;  $\chi^2 (1, N=105)=8.0, p = .005$  respectively).

Is cancer specific distress related to who provides a blood sample for genetic testing?

We also evaluated the bivariate association between cancer-specific distress, as measured by the IES intrusion subscale, and the provision of a blood sample for genetic testing. In order to examine the hypothesized curvilinear relationship between distress and provision of a blood sample, we categorized scores into low distress (IES 0-1, N=46), moderate distress (IES 2-9, N=30), and high distress (IES 10+, N=29), following the cutoff points established by Lerman and colleagues (15). As shown in Table 1, women with moderate distress scores were more likely to

provide a blood sample than women with low or high distress scores ( $\chi^2$  (1, N=105) = 9.25,  $p = .01$ ).

Is cancer specific distress related to who provides a blood sample after controlling for demographic and risk variables?

To determine whether cancer-specific distress predicted blood sample provision after controlling for potential confounders, we conducted a logistic regression analysis with hierarchical variable entry. On the first step we entered all of the variables with significant ( $p < .10$ ) associations with blood sample provision (age, perceived risk, objective risk). On the second step, we entered cancer-specific distress which was dummy coded with moderate distress serving as the reference cell. The results of this analysis are displayed in Table 2.

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Insert Table 2 about here  
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Age, perceived risk and objective risk, taken together, significantly predicted blood sample provision ( $\chi^2$  change (3, N=105) = 14.9,  $p = .002$ ). Cancer-specific distress, entered on step 2, added significantly to the prediction of blood provision ( $\chi^2$  Change (2, N=105) = 13.32,  $p < .01$ ). Inspection of the final odds ratios supported our prediction of a curvilinear relationship between distress and blood provision. Specifically, women with low levels of cancer-specific distress were less likely to provide a blood sample compared to women with moderate levels of cancer-specific distress (OR=.24, 95% CI=-0.5, 0.1 ). Similarly, women with high levels of cancer-specific distress were less likely than those with moderate levels of distress to provide a blood sample (OR=.11, 95% CI=0.4, 0.03). In addition to cancer-specific distress, objective risk and perceived

risk also were independently associated with blood provision (OR=4.4, 95% CI=18.5, 2.7; OR=2.5, 95% CI=6.7, 2.7 respectively). Specifically, women with higher levels of objective risk were about four times more likely to provide blood for genetic testing than women with lower levels of objective risk. In addition, there was a trend suggesting that women with higher levels of perceived risk were more likely to donate blood for genetic testing than women with lower levels of perceived risk.

### Discussion

The results of the present study indicate that cancer-specific distress is related to women's decisions to donate blood for BRCA1 testing. Women with moderate levels of cancer specific distress were more likely to donate blood than women with high or low levels of cancer specific distress. These results were obtained after controlling for age, objective risk and perceived risk, which were all positively related to provision of a blood sample for genetic testing.

The finding of a curvilinear relationship between cancer-specific distress and provision of a blood sample for BRCA1 testing is inconsistent with the finding reported by Lerman and colleagues (17) that individuals with high levels of cancer-specific distress were more likely to request BRCA1 test results than individuals with moderate or low levels of cancer-specific distress. There are at least three possible explanations for these discrepant findings. First, unlike the subjects in the present study, the participants in the study by Lerman et al. (17) included both affected and unaffected male and female members of previously studied HBOC families having extensive histories of breast cancer. Also, unlike participants in the present study who donated blood at the time of the study to learn their mutation status, the members of these HBOC families had donated blood several years earlier as a part of an investigation to localize the BRCA1 gene.

Moreover, unlike participants in the present study, the members of the HBOC families were aware that a BRCA1 mutation had been found in their family. It is therefore possible that cancer-specific distress plays a different role in the decision to undergo genetic testing among members of these well-studied high risk families than among individuals in the present study who came from families with much less extensive family histories of breast cancer and who did not know if there was a BRCA1 mutation in their family. Second, cancer-specific distress may differentially affect the decision to provide a blood sample for genetic testing versus the decision to request test results. However, this is an unlikely explanation, as BRCA1 test results are now available for 34 of our participants, and none of them have declined to learn their mutation status. Third, the participants in these two studies could have had different levels of cancer-specific distress (IES). However, this is an unlikely explanation because the cancer-specific distress levels among participants in the present study showed a similar distribution ( $M=6.3$ ,  $SD=7.5$ ) to that reported by Lerman and colleagues (17) ( $M=6.2$ ,  $SD=6.7$ ). The finding in the present study that older women were more likely to provide a blood sample for genetic testing than younger women is also inconsistent with Lerman and colleagues (17) finding that younger women were more likely to request their BRCA1 test results. As with cancer-specific distress these discrepant results may be due to the fact that the subjects in the present study differed on several variables from the participants in Lerman and colleagues (17) study. Additional studies are needed to confirm the possibility that psychosocial variables (e.g., cancer-specific distress), as well as demographic variables (e.g., age), may differentially effect the decision to undergo genetic testing depending upon the population studied.

Whether the relationship between distress levels and the decision to undergo testing is



linear or curvilinear, the results of the present study support an emerging consensus that distress may be an important variable to consider as we try to understand individuals' decisions to undergo testing. The data reported here revealed a significant relationship between cancer-specific distress levels and testing decisions even after controlling for other previously published predictors (e.g., age, objective risk, perceived risk). Cancer-specific distress has also been found to affect the effectiveness of genetic counseling. Lerman and colleagues (26) found that women who had high levels of cancer-specific distress were more likely to continue to overestimate their lifetime risk of developing breast cancer after the risk counseling than women with low levels of cancer-specific distress. In addition, cancer-specific distress may play a role in the notification of BRCA1 test results as suggested by a recent study (28) which found that individuals with mutation in the BRCA1 gene reported significantly higher levels of cancer-specific distress than individuals found to be noncarriers. Take together, the results from these studies and the present study suggest that cancer-specific distress needs to be addressed in the context of genetic testing. Understanding the role of cancer specific-distress in genetic testing will assist in designing interventions which will increase the probability that individuals are making an informed decision about undergoing genetic testing for breast cancer susceptibility and minimize the possible negative psychological impact of genetic testing.

Consistent with previous studies which found that intentions to undergo genetic testing were related to high levels of perceived risk (13,14) the present study found that women with high levels of perceived risk were more likely to provide a blood sample for genetic testing. This finding further indicates the importance of addressing cancer-specific distress, as genetic counseling may not be effective in improving risk comprehension among women with high levels

of cancer-specific distress (26).

The results of the present study should be interpreted cautiously for several reasons. First, as a majority of the women were White and well educated, we can not generalize our findings to individuals from other ethnic and sociodemographic backgrounds. Second, because of the small sample size we could not examine in the logistic regression analyses whether the relation between cancer-specific distress and provision of blood sample differed between women who were recruited from a special surveillance breast program and women who were self-referred for genetic counseling. However, the results from the bivariate analyses, computed separately for each recruitment site, indicated that, at both recruitment sites, women with moderate levels of cancer-specific distress were more likely to provide blood samples than women with low or high levels of cancer-specific distress. Third, the generalizability of these findings to BRCA2 test use needs to be examined as the BRCA2 gene had not been cloned when the present study started.

Despite these limitations, the results of the present study indicate the importance of understanding the role of cancer specific-distress in women's decisions to undergo genetic testing for breast cancer susceptibility.

Table 1: Bivariate Associations With Provision of a Blood Sample for BRCA1 Testing

Variable	Reference group	% providing blood
Age	<50	49 <sup>+</sup>
	≥ 50	69
Education	< College	57
	≥ College	55
Marital status	Married	59
	Unmarried	50
% objective risk	< 40	43 <sup>**</sup>
	≥ 40	71
% perceived risk	<70	48
	≥70	68 <sup>*</sup>
Cancer-specific distress	Low distress	52 <sup>**</sup>
	Moderate distress	77
	High distress	38
<sup>+</sup> p < .10 <sup>*</sup> p < .05 <sup>**</sup> p < .01		

**Table 2: Hierarchical Logistic Regression Predicting Provision of a Blood Sample for BRCA1 Testing**

Step and variables	Reference group	$\chi^2$	Odds ratio	95% CI
<b>Step 1</b>				
Age	<50 ≥ 50	14.9	2.4 <sup>+</sup>	6.1, 0.98
objective risk	< 40 ≥ 40		3.1**	7.3, 1.32
perceived risk	<70 ≥70		2.1 <sup>+</sup>	5.2, 0.99
<b>Step 2</b>				
Cancer-specific distress	Low distress	13.3*	.24**	0.54, 0.11
	High distress		.11*	0.42, 0.03

Note CI=Confidence Interval

<sup>+</sup>p < .10, \*p < .01, \*\*p < .001

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